THEMES RELATED TO CHILDREN LIVING WITH HIV/AIDS

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DECLARATION

I, the undersigned, hereby declare that the work contained in this assignment is my own original work, and that I have not previously in its entirety or in part submitted it at any university for a degree.

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Signature **Date**

ABSTRACT

This review examines themes related to children, especially children under the age of fifteen, living with HIV/Aids. For review purposes themes include defining children living with HIV/Aids as a vulnerable population, the psychological impact of HIV/Aids on children, children's coping with and perceptions of HIV/Aids. The global HIV/Aids pandemic has caused major worldwide social change. The impact, especially the psychological impact of HIV/Aids on children appears to be vast and at times disastrous in nature. HIV/Aids is estimated to affect the lives of several generations of children and the impact of the pandemic will therefore characterize their communities for decades to come as the numbers of affected and infected children are on the increase. It has been noted by research done that children living with HIV/Aids become impoverished, their insecurities worsen and their psychosocial and psychological problems increase. In addition their educational and work opportunities decline, their nurturing and support systems disintegrate, and child mortality rates rise. The necessity of psychological support for children affected and infected by HIV/Aids is directly linked to the rights of children listed in the United Nations Convention on the Rights of the Child and the South African Constitution. Research reviewed points out that a child's physical and psychological health is intertwined and therefore a child cannot be physically healthy without also being psychologically secure. Research reviewed also points out that it is of the utmost importance that the voices of children who live with HIV/Aids are heard, their involvement in decision making and planning related to HIV/Aids is allowed and that their needs are met, especially their psychological needs in relation to the pandemic. Overall the literature reviewed in the past four years (2003-2006) highlights the significantly under-investigated, under-researched themes such as psychological aspects related to children living with HIV/Aids, both in South Africa and internationally. These aspects surrounding HIV/Aids, as previously mentioned, also seem to be the least tangible and the most difficult for adults to address or comprehend fully and yet they impinge on all aspects of developing children - hence the identified need in this area for adequate research and psychological support, such as program implementation.

OPSOMMING

Hierdie literatuuroorsig bied ’n ondersoek na die wêreldwye sosiale verandering en uitwerking wat die globale HIV/vigs-pandemie tot gevolg het. Daar word veral gelet op temas wat verwantskap hou met kinders, veral kinders vyftien jaar oud en jonger wat leef met HIV/vigs. Temas sluit in die definiëring van kinders as weerloos, kinders se hantering van HIV/vigs, hulle persepsies van HIV/vigs en hulle sielkundige behoeftes en ander aspekte met betrekking tot HIV/vigs. Die trefkrag van HIV/vigs blyk omvattend en by tye rampspoedig te wees. Na beraming beïnvloed HIV/vigs verskeie geslagte van kinders en die uitwerking van die pandemie sal dus dekades lank nog deel vorm van hulle gemeenskappe soos die aantal kinders wat geïnfekteer en geaffekteer is, toeneem. Navorsing toon dat kinders wat met HIV/vigs leef, verarm. Verder vererger hulle onsekerhede en hulle psigososiale en sielkundige probleme neem toe. Ook neem die kinders se opvoedkundige en werkgeleenthede af, hulle versorgings- en ondersteuningsnetwerke disintegreer en sterftesyfers neem toe. Die noodsaaklikheid van sielkundige ondersteuning vir kinders wat deur HIV/vigs geïnfekteer en geaffekteer is, word direk in verband gebring met die regte van kinders soos gelys in die Verenigde Nasies se Konvensie oor die Regte van die Kind en die Suid-Afrikaanse Grondwet. Die literatuuroorsig toon dat ‘n kind se fisieke en sielkundige gesondheid ten nouste met mekaar verband hou en daarom kan ’n kind nie fisiek gesond wees sonder om ook sielkundig geborge te wees nie. Verder dui navorsing ook op die kardinale belang daarvan dat kinders wat leef met HIV/vigs se stemme gehoor word, hulle betrokkenheid by besluitneming en beplanning verseker word en al hulle behoeftes bevredig word, veral hulle sielkundige behoeftes wat met die pandemie verband hou. Oor die algemeen beklemtoon die literatuuroorsig wat oor die afgelope vier jaar strek (2003-2006) dat daar nie voldoende navorsing gedoen is met betrekking tot temas wat verwantskap hou met kinders en HIV/vigs nie, nie alleen in Suid-Afrika nie, maar ook internasionaal. Hierdie bevindings is kommerwekkend veral omdat Suid-Afrika ‘n land is met onrusbarende groot getalle kinders wat deur HIV/vigs geïnfekteer is. Dit wil ook voorkom of hierdie aspekte wat te make het met kinders en HIV/vigs nie baie duidelik is vir volwassenes nie en ook die moeilikste is om te hanteer of ten volle te verstaan, hoewel dit alle aspekte van die kind se ontwikkeling raak. Vandaar die behoefte op hierdie gebied aan voldoende navorsing en sielkundige ondersteuning, soos program implementering.

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1. INTRODUCTION

"Children have their own world. For us it is small, for them it is Everything." -Dennis Bamwenzaki, teacher trainer, HUMULIZA, Nshamba, United Republic of Tanzania (Fox, Anderson, Sozi & Delate, 2001, p. 28).

1.1 Children living with HIV/Aids

Literature reviewed indicates that the global HIV/Aids pandemic has caused major worldwide social change. The psychological impact of HIV/Aids on children, especially children under the age of 15, appears to be especially significant and at times disastrous in nature (UNAIDS, 2002, 2006; World Health Organisation (WHO), 2000-2004a). According to revised estimates taken from 11 Sub-Saharan African countries, 20-30 percent of children under the age of 15 will be orphaned by the year 2010 due to the HIV/Aids pandemic (Human Sciences Research Council (HSRC), 2003; UNAIDS, 2004, 2006). Projections estimate that African children will be orphaned even if numerous support initiatives are put in place to slow down the destructive process of HIV/Aids (Family Health International, 2005). In South Africa alone, estimates of the number of children living with HIV/Aids, such as orphans, are projected to rise substantially (Giese & Meintjies, 2003a). In 2003 there was an estimated 2.2 million orphaned children (12 percent of all children) and it is expected that by 2010 the number will have risen to 3.1 million (18 percent of all children). By 2015 the number is estimated to increase to 5.7 million. It is further estimated that more than 2 million children in South Africa are currently infected with HIV/Aids (Bradshaw, Johnson, Schneider, Bourne & Dorrington, 2002; Family Health International, 2005; HSRC, 2003; UNAIDS, 2004; 2006).

It is nonetheless apparent that the overall number of children affected by and infected with HIV/Aids seems to be poorly documented in South Africa at present (Wilson, Giese, Meintjies, Croke & Chamberlain, 2002). One can nevertheless assume from the available and projected statistics on orphaned and infected children, that the overall number of children living with HIV/Aids is extremely high (Family Health International, 2005; UNAIDS, 2004, 2006).

Research has indicated that the impact of HIV/Aids on children is cause for concern. Children are becoming impoverished, their insecurities are worsening, their psychological problems are increasing, their educational and work opportunities are decreasing, their nurturing and

support systems are disintegrating, and their mortality rates are increasing (Bradshaw et al., 2002; Family Health International, 2005; HSRC, 2003; UNAIDS, 2004).

It can thus be concluded from available and projected statistics and research that the HIV/Aids pandemic will affect the lives of generations of children to come. As a result the pandemic can in the future be expected to have a growing influence on children's communities as the number of children living with HIV/Aids increases (HSRC, 2003; UNAIDS, 2004, 2006).

1.2 The rights of vulnerable children

In 1990 the United Nations Convention on the Rights of the Child (UNAIDS, 2002; Wilson et al., 2002) was established. The main principle underscoring the Convention was that support for children should be in the best interest of children. According to this principle all children must be regarded as being of equal worth and vulnerable children need special support to be able to enjoy full human dignity. Furthermore, children have the right to be heard and to be sheltered from abuse, neglect, maltreatment, and exploitation. Because children's needs are quite complex and multi-faceted, special attention must be given to their specific needs, such as their economic, social, educational, medical and psychosocial/psychological needs (Family Health International, 2005; HSRC, 2003; UNAIDS, 2004).

Section 28 of the South African Constitution (Prinsloo & Beckmann, 2000), the National Integrated Plan for Children and the HIV/AIDS/STD Strategic Plan for South Africa 2000-2005 (Desmond & Gow, 2002; Giese & Meintjies, 2003b; Meintjies & Giese, 2004), all emphasise the importance of adequate support for children, but especially support for at risk/vulnerable children such as children living with HIV/Aids. Legislation and planning mention that society must try by all possible means to ensure children's educational, physical, mental, spiritual, moral and social development and well-being. These policies and plans share similar sentiments in their advocacy that children have the right to participate in decision-making processes, either directly or through appropriate representation (Family Health International, 2005; Giese & Meintjies, 2003b; Health Economics And HIV/AIDS Research Division (HEARD), 2002; HSRC, 2003; UNAIDS, 2002, 2004; WHO, 2000-2004a).

1.3 The need for research and psychological support

For review purposes, themes related to children living with HIV/Aids include all issues related to children's mental/psychological well-being or development, such as their psychological

needs at different ages, how they develop, how they cope with certain stressors or trauma and their perceptions of different aspects that all impact greatly on their psychological well-being (Bradshaw et al., 2002; Family Health International, 2005; Fox et al., 2001; HEARD, 2002; HSRC, 2003; UNAIDS, 2004; WHO, 2000-2004a; Wilson et al., 2002).

The necessity for the spotlight to be on relevant themes relating to psychological aspects of children living with HIV/Aids and psychological support for these children is thus underscored by the rights listed in the United Nations Convention on the Rights of the Child (UNAIDS, 2002; Wilson et al., 2002), the South African Constitution (Prinsloo & Beckmann, 2000) and numerous other policies and plans.

The question could be asked why the focus on themes related to psychological aspects and support for children living with HIV/Aids should be important. Research reviewed has pointed out that a child's physical and psychological health is intertwined. The physical health of a child is therefore important and co-dependent on the child being psychologically secure (Fox et al., 2001; HSRC, 2003; Wilson et al., 2002).

Research further emphasises the importance of the voices of children living with HIV/Aids being heard. Their involvement in decision making and planning should be permitted and their needs met, especially their psychological needs (Fox et al., 2001; The Children's Institute, 2003-2004).

Research reviewed further suggests that psychological aspects of children living with HIV/Aids have been grossly neglected (Family Health International, 2005). Themes relating to psychological aspects such as the psychological coping of children with HIV/Aids, their perceptions and their psychological needs related to HIV/Aids have not been adequately addressed in Africa, but especially in South Africa (Family Health International, 2005). The psychological aspects surrounding HIV/Aids, as formerly mentioned, also seem to be the least tangible, the most difficult for adults to address or comprehend fully and discuss with young children (Fox et al., 2001). This is of concern because psychological aspects surrounding HIV/Aids impinge on all areas of a developing child. That is why the need for adequate research and support initiatives such as programme development has been identified (Family Health International, 2005; Fox et al., 2001; HEARD, 2002; HSRC, 2003; UNAIDS, 2002; 2004; WHO, 2000-2004a; Wilson et al., 2002).

Research and support initiatives, such as the implementation of psychological support programmes, appear to be especially important when confronted with a threat such as HIV/Aids (Gilborn et al., 2006). It is therefore necessary to understand all attributes related to the pandemic, its multi-faceted impact on children and their coping with and perceptions of HIV/Aids in order to be able to develop effective and sustainable efforts to lessen the impact of HIV/Aids on children (Family Health International, 2005; Foster & Williamson, 2000).

Society must strive to respect, protect and fulfil children's rights despite the daunting numbers of children living with HIV/Aids. Children affected by and infected with the epidemic can still have safe, healthy and productive childhoods, but only if all sectors of society respond with immediate, sustained and coordinated support efforts (Giese, Meintjies, Croke & Chamberlain, 2003).

It is strongly felt that without the appropriate research and understanding of aspects related to HIV/Aids, South African efforts will be to no avail whilst the pandemic continues to ravage society and especially children. Thus large-scale and sustainable long-term support efforts are necessary to enable the South African society to better cope with these severe realities (Bradshaw et al., 2002; Family Health International, 2005; Fox et al., 2001; HEARD, 2002; HSRC, 2003; UNAIDS, 2004; WHO, 2000-2004a, b; Wilson et al., 2002).

1.4 The goals of the current paper

This current literature review attempts to focus on some themes related to children living with HIV/Aids. For review purposes themes include the definition of children living with HIV/Aids, under the age of 15 years, as a vulnerable population; the psychological impact of HIV/Aids on children; children's coping with HIV/Aids, and their perceptions of HIV/Aids.

The review attempts i) to point out the importance of taking into consideration psychological aspects of children living with HIV/Aids (such as their coping and perceptions) when doing research and planning psychological support initiatives such as programme development, ii) to notify the reader of the literature about psychological aspects, and iii) to clarify areas of research that need to be further explored, so as to promote research and achieve adequate psychological support. The belief is that research and psychological support, such as psychological programme implementation, will only have an ameliorating effect on the suffering of children living with HIV/Aids when the psychological aspects of children living with

HIV/Aids are thoroughly explored and the necessary support structures are in place (Fox et al., 2001; O' Brien, 2004).

The review will start with the defining of key theoretical concepts and the methodological approach used in the review of literature. The review will further focus on the definition of children living with HIV/Aids as a special and vulnerable population. Attention will also be given to the findings of literature reviewed that encompass the psychological impact of HIV/Aids on children, children's coping with HIV/Aids and their perceptions regarding HIV/Aids. The paper will be concluded with recommendations for research and support initiatives such as programme development related to psychological aspects of children living with HIV/Aids.

2. DEFINING KEY CONCEPTS

2.1 Vulnerable children

Research reviewed suggests that South African children and young people in general are extremely vulnerable to HIV/Aids. Reasons stated for South African children's high vulnerability are the alarming conditions that characterise society such as unemployment and poverty, sexual exploitation and abuse, violence and trauma, and the lack of adequate access to HIV/Aids information and support services. Alarming conditions of this nature compel the South African society to define a large number of children as a special, at risk and vulnerable population, especially children living with HIV/Aids (Berry & Guthrie, 2003; Foster & Williamson, 2000; WHO, 2000-2004a).

Various South African researchers such as Johnson and Dorrington (2001), Richter, Manegold and Pather (2004) and Skinner et al. (2004) make use of the following definition of vulnerable children, which includes children living with HIV/Aids: vulnerable children can be defined as a special population of children or categories of children with specific and unique needs (Skinner et al., 2004) such as orphans (maternal, paternal or double orphans); neglected, destitute or abandoned children; children who have terminally ill parents or caregivers; children who are born of a teenage or single mother; children who are living with a parent or caregiver who has insufficient means or opportunities to generate an income or who is unemployed; children who are abused by a relative/parent or caregiver; children who are disabled, and children under the age of 15 who have lost their mother or caregiver (Johnson & Dorrington, 2001; Richter et al., 2004; Skinner, et al., 2004; Wilson et al., 2002).

2.2 Children living with HIV/Aids

The HIV/Aids pandemic impacts differently on different children and within this special population creates two main categories, under which sub-categories fall. The two main categories are children affected by HIV/Aids and infected with HIV/Aids. Children affected by HIV/Aids can be defined as all children who are directly or indirectly impacted by the pandemic. This means children who have not contracted the HIV virus and thus are not HIV positive, but who have parents, siblings, family or friends who have the virus and are thereby experiencing the emotional, financial, and social consequences of the virus in their daily living. Children infected with HIV/Aids are children who are HIV positive and who have contracted the virus, for example via their mother at birth, or who have been sexually abused by a person who is HIV positive (Meintjies & Giese, 2004; Skinner et al., 2004; UNAIDS, 2006).

A further sub-category includes children with an infected parent or family member. Then the category of a maternal or paternal orphan also occurs. This category can include a child who has lost one parent - a mother or father respectively. Also included in this definition is a double orphan who has no living parent. Finally, there are also children living in child-headed households. Children living in child-headed households are children who have lost both their parents or, alternatively, both parents are ill. Usually, the oldest children in the household take up the role of parents and provide for themselves and their siblings or other dependents in the house (Meintjies & Giese, 2004; Skinner et al., 2004; UNAIDS, 2006).

2.3 The psychological impact of HIV/Aids on the well-being of children

Themes such as psychological aspects of children living with HIV/Aids, which include their psychological needs at different ages, how they develop, how they cope with certain stressors or trauma and their perceptions of different aspects, all impact greatly on their psychological well-being (Bradshaw et al., 2002; Family Health International, 2005; Fox et al., 2001; HEARD, 2002; HSRC, 2003; UNAIDS, 2004; WHO, 2000-2004a, b; Wilson et al., 2002).

The impact that HIV/Aids has on children appears to be complex and interconnected with all aspects of life, including most areas of children's development and well-being. The interrelationship of HIV/Aids with other problems of child development has become more apparent, but the long-term impact of HIV/Aids is still not fully understood, especially the

psychological impact and how children of different age groups and contexts cope with HIV/Aids (Family Health International, 2005; Richter et al., 2004; UNAIDS, 2002 - 2006).

According to Fox et al. (2001) and the Human Sciences Research Council (2003) the potential psychological impact of HIV/Aids on children is often the increased psychological distress resulting from the loss of family and therefore a loss of a person's sense of identity. This often leads to depression and overall reduced well-being. Many children experience the loss of educational opportunities, forced migration, and increased street living. Deteriorating living conditions often lead to an increased risk to the exposure of HIV infection and abuse. Many children experience continuous grief, illness and death, which often leads to children developing anxiety about their future, experiencing diminished love, attention and affection, being separated from siblings and being removed from school. Many children also experience ongoing isolation and discrimination due to the stigma attached to HIV/Aids (Johnson & Dorrington, 2001; Richter et al., 2004; UNAIDS, 2006; WHO, 2000-2004a, b).

2.4 Children's coping

Upon reviewing literature of the past 4 years on children's coping with HIV/Aids it proved difficult to define the concept of coping related specifically to HIV/Aids. Research seems to have been focused on various aspects of adolescent and adult coping with HIV/Aids and not so much on children's coping or on defining the concept of coping in relation to children living with HIV/Aids (Kemppainen et al., 2006; Rotheram-Borus, Weiss, Alber & Lester, 2005). Literature regarding children's coping has focused mainly on children's coping with trauma, such as divorce, death, abuse, illness, or medical procedures (Compas, Conner-Smith, Saltzman, Harding Thomsen & Wadsworth, 2001).

Researchers such as Compas et al. (2001) have defined coping as the ability of children to apply constantly changing cognitive and behavioural efforts to manage specific internal and/or external demands that they appraise as taxing or exceeding their own resources.

Ayers, Sandier, West and Roosa (1996) indicated a four factor model of children's coping, which includes active, distractive, avoidant and support-seeking coping. Reber (1995) defined coping strategies as the conscious or, at times, unconscious rational or irrational ways of dealing with the anxieties of life - strategies designed to deal with the source of anxiety.

Kemppainen et al. (2006) suggested that coping implies a person's self-care or management strategies, which could include self-comforting behaviours, help-seeking behaviours, self-talk, avoidance, or unhealthy coping behaviours.

Because the HIV/Aids process implies stress, trauma, loss, death and illness this review suggests that these definitions could be used and adapted when focusing on children's coping with HIV/Aids.

From the reviewed literature it can deduced that adequate coping skills and support are very important aspects regarding children's overall well-being. It is therefore of the utmost importance that the psychological needs of children (Wilson et al., 2002), such as their attachment needs, self-actualisation/identity needs and their needs regarding guidance and boundaries are met in order for them to develop adequate coping skills and to experience psychological and overall well-being. The lack of adequate coping skills and proper environmental support might lead to unfulfilled needs, which in turn might lead to psychological problems and overall unwellness (Compas et al., 2001; Kemppainen et al., 2006).

2.5 Children's perceptions

Reviewed literature of the past 4 years suggests that researchers have not necessarily focused on defining the concept of children's perceptions of HIV/Aids but seem to associate perception broadly with a person's, in this case a child's, knowledge, attitude, insight, understanding, awareness or concerns regarding a specific topic such as HIV/Aids (Pakenham, Bursnall, Chiu, Cannon, & Okochi, 2006; Raman & Gelman, 2005; Rotheram-Borus et al., 2005; Wooding, Cancelli, Ponterotto, & Keitel, 2005).

A definition of perception, according to Reber (1995), is that it refers to the actual experiencing or awareness of stimuli or processes, which can include physical, physiological, neurological, sensory, cognitive or affective components.

Researchers, such as Pakenham et al. (2005) and Raman & Gelman (2005), seem to make use of a more general definition of perception in relation to HIV/Aids.

It is suggested by this review that these definitions could be used and adapted when focusing on children's perceptions of HIV/Aids.

Research done by researchers such as Fox et al. (2001) and The Children's Institute (2003-2004) suggests that it is very important to take children's perceptions of living with HIV/Aids into consideration. The perceptions, attitudes and beliefs of children of different ages, genders, cultures, vulnerability categories and contexts will also develop differently and change over time and may need to be considered for research and support initiatives such as programme development (Peltzer, 2003; Peltzer & Promtussananon, 2003).

3. METHODOLOGY

The review is not an exhaustive study on all prior literature concerning themes related to children living with HIV/Aids. The review only focuses on the most current literature, both internationally and in South Africa, over the past 4 years (2003-2006). The review focuses, as mentioned earlier, on the definition of children living with HIV/Aids as a special and vulnerable population; the psychological impact of HIV/Aids on children; children's coping with HIV/Aids, and children's perceptions of HIV/Aids. Attention will also be given to recommendations for research and support initiatives such as psychological programme implementation including themes relating to psychological aspects of children living with HIV/Aids. The following is a list of several of the accredited journals and official reports that were reviewed:

Accredited Journals

Journal of Child and Adolescent Mental Health; South African Journal of Psychology; European Journal of Social Psychology; International Journal of Psychology; Journal of Abnormal Child Psychology; American Psychologist; Journal of Family Psychology; Psychological Review; Journal of Clinical Psychology; Journal of Child Psychology and Psychiatry; Journal of Psychology; Child Development; Developmental Psychology; Journal of HIV/Aids; Journal of Consulting and Clinical Psychology; American Journal of Orthopsychiatry; Rehabilitation Psychology & Health Psychology.

Official Reports

The National Household HIV Prevalence and Risk Survey of South African Children (Brookes, Shisana & Richter, 2004); A situational analysis of orphans and vulnerable children in four districts of South Africa (Davids & Skinner, 2005); Children are the future, give them their rights, Submission to the Parliamentary Portfolio Committee on social development – on the Children's Bill (The Children's Institute, 2003-2004); Children on the Brink 2002 – A joint

report on orphan estimates and program strategies (UNAIDS, 2002); Aids and Orphans: A tragedy unfolding. Report on the Global Aids epidemic, 4th global report (UNAIDS, 2004); The impact of Aids on people and societies, chapter 4. Report on the Global Aids Pandemic (UNAIDS, 2006); Mental Health and HIV/Aids, Report on a round-table discussion March 2003 (HSRC, 2003).

Short summary of findings from reviewing the literature

Overall, the review of the literature over the past 4 years (2003-2006) highlighted the significantly under-investigated research on the abovementioned themes relating to psychological aspects of children living with HIV/Aids, both in South Africa and internationally. The major concern related to these findings is that the severity and the impact of the pandemic are increasing and the current and projected statistics for children living with HIV/Aids are on the increase. In South Africa alone the pandemic is cause for major concern and therefore one would expect that more recent research would be devoted to aspects impacting on children and more specifically themes relating to psychological aspects of children living with HIV/Aids. Even though numerous role players, including the South African Government, have stressed the importance of this type of research and support initiatives such as programme development, not much seems to have been done.

More specific findings from the review are discussed at length under each aspect mentioned.

4. FINDINGS

4.1 Children living with HIV/Aids as a vulnerable population

Various characteristics of the South African context suggest that South African children, especially children under the age of 15 and young people are often more vulnerable to HIV/Aids than children from various other countries. The diverse cultural and individual characteristics of South African communities and individuals, wide-spread poverty, high statistics of sexual abuse, exploitation and violence in our communities, and the lack of access to adequate health and mental health services are all factors that contribute to making South African children a vulnerable and special population (Berry & Guthrie, 2003). Children living with HIV/Aids are often made more vulnerable by the attitudes and behaviours of significant or influential adults in their lives, such as their parents, teachers, the Government, community leaders, and service providers. These role players often do not adequately provide

psychological support for children living with HIV/Aids in the form of effective support initiatives such as programmes, research, policies and legislation (Berry & Guthrie, 2003; Foster & Williamson, 2000; WHO, 2000-2004a, b).

The role of the extended family and community in caring for children living with HIV/Aids in South Africa is furthermore in a state of flux. South Africa is becoming more urbanised and in addition to urbanisation the extended family as a safety net for children has weakened. Children are often neglected and end up in vulnerable situations. Various children end up living on the street or drop out of school and start working to survive. As a result, child-headed households seem to become the norm (Foster & Williamson, 2000).

Children infected and affected by HIV/Aids are encountered widely in South Africa but very few forms of adequate assistance and support exist. This compels South African society to define a large number of children in our country as a special, at risk and vulnerable population, especially children infected and affected by HIV/Aids (Berry & Guthrie, 2003; Foster & Williamson, 2000; WHO, 2000-2004a, b).

Researchers such as Meintjies and Giese (2004) have shown that to date, much of the attention paid to children's vulnerability due to the HIV/Aids pandemic has focused mainly on providing support to orphans. It is strongly felt by researchers such as Meintjies & Giese (2004) and Skinner e al. (2004) that an approach to HIV/Aids that focuses only on orphans, as a special and vulnerable population, is not adequate in the South African context. Various researchers such as Skinner et al. (2004) have stated that an approach focusing on support for orphans only is not appropriate. Orphanhood and the vulnerability of children can be viewed as a process that begins well before a child experiences the death of a parent or caregiver with differently amalgamated vulnerabilities at different points along a continuum (Meintjies & Giese, 2004; Skinner et al., 2004; UNAIDS, 2006).

The HIV/Aids pandemic impacts differently on children and creates two main categories with various sub-categories within this special population.

The two main suggested categories according to this review are children affected by HIV/Aids and those infected with HIV/Aids, with further sub-categories, such as maternal, parental or double orphans and child-headed households (Meintjies & Giese, 2004; Skinner et al., 2004; UNAIDS, 2006).

According to literature, the category of vulnerable children can be as broad or as narrow as required by a specific context. Researchers such as Johnson and Dorrington (2001) and Wilson et al. (2002) have proposed that the Government and role players should adopt a bottom-up approach when considering vulnerable children. The bottom-up approach implies that these role players should not, as in the past, always obtain their information on communities and children's needs from certain elite community members, NGO staff, and State service representatives. The Government and all role-players should take guidance from the community and especially children themselves when setting parameters for addressing the needs of vulnerable children. It is further suggested that the Government and role-players determine the importance of addressing the specificity of the identified needs versus aspects that are bureaucratically feasible, sustainable and have a longer-term impact. It is very important to take into consideration the resource limitations in the specific context when determining who should be included in the category of vulnerable children. In this way allowance is made for local definitions of vulnerability to form a fundamental part of psychological support, such as programme development. Every community is different and requires that various significant role players from within and from outside the community agree as to which groups of children can be viewed as vulnerable in a specific context. In defining vulnerability, consensus needs to be reached as to which groups or categories of children are thought to be most vulnerable within a particular context. It is of critical importance that local role players and children are involved in this process and in decisions made regarding the kind of support that would be most appropriate to assist these children (Johnson & Dorrington, 2001; Richter et al., 2004; Skinner et al., 2004; Wilson et al., 2002).

In South Africa a working definition of vulnerable children, especially children under the age of 15 and children living with HIV/Aids, includes orphans; neglected or abandoned children; children with parents or caregivers who are terminally ill; children with a teenage or single mother; children living with a parent or caregiver with insufficient means or opportunities to generate income or who is unemployed; abused children; disabled children, and children under the age of 15 who have lost their mother or caregiver (Johnson & Dorrington, 2001; Richter et al., 2004; Skinner, et al., 2004; Wilson et al., 2002).

Although, according to Johnson & Dorrington (2001) and Wilson et al. (2002), many service providers often have the opportunity to come into contact with children and their caregivers, they do not seem to use the opportunities presented to them effectively. These opportunities

of contact could be used to identify, refer, support and/or monitor children who may be prone to vulnerability. Often the responsibility for the identification and support of vulnerable children is placed with governmental organisations and staff, social workers, service providers from outside the community, volunteers, and NGOs. The problem herein is that these various role-players do not always have the resources to respond adequately and punctually to warning signs in children. It seems that as children become increasingly vulnerable, opportunities to come into contact with them also often become less frequent (Johnson & Dorrington, 2001; Richter et al., 2004; Wilson et al., 2002).

Researchers such as Johnson and Dorrington (2001) and Wilson et al. (2002) identified some factors that appear to impede on the identification, referral, support and monitoring of vulnerable children affected by and infected with HIV/Aids. According to Johnson and Dorrington (2001), Richter et al. (2004) and Wilson, (2002) they are the following:

- The inadequate consciousness surrounding the impact of HIV/Aids on children and, more specifically, the impact of HIV/Aids on children within a particular facility's immediate and adjacent area.
- The extremely demanding working conditions and inadequate support for numerous service providers.
- The poor history taking by service providers does often not elicit enough information on the socio-economic and psychological vulnerabilities of patients, particularly concerning children.
- Health facilities and other services are often not accessible to all vulnerable children, especially those children from rural areas where clinics and households are far apart and transport is scarce. Also when these services or transport are available and accessible they are often too expensive.
- Basic and essential pharmaceuticals and equipment are frequently not available or only available in insufficient quantities.
- Negative health-worker and service-provider attitudes towards patients or child patients also can have an undesirable impact. The attitude of some health workers and service providers is seen as a barrier to accessing services and to the constructive discussion of problems and challenges faced.

- Negative patient attitude towards service providers.
- Inadequate or no training for service providers regarding talking to, identifying and counselling vulnerable children.
- A poor capacity for the implementation of home visits.
- The poor infrastructure (vehicles, telephones) at clinics and other facilities impedes follow-up care and referrals.
- Little collaboration between health facilities and other significant or possible role players with the capacity to assist vulnerable children and their caregivers.
- Relationships between clinic-based health-care workers, different service providers, and community volunteers/home-based carers are often strained.
- Health workers, service providers, and patient's poor knowledge about services that exist within their immediate and adjacent area.
- The existence of inefficient people or organisations to which vulnerable children are often referred for assessment or support.
- An excessive reliance on certain overburdened service providers, such as social workers, for the support of children.
- The stigma and discrimination around HIV/Aids often inhibits disclosure and help-seeking behaviours.
- Confidentiality agreements often prevent effective referral of patients and vulnerable children affected by and infected with HIV/Aids to services that could provide them with the necessary support.
- Poor awareness of the guidelines that exist for the treatment and care of HIV/Aids infected and affected children.
- Many health workers and other service providers are overburdened and many see the identification, monitoring, and support of vulnerable children as an additional and overwhelming task.
- Reluctance to treat unaccompanied children.
- The lack of focus on possible indicators of social need and vulnerability.

- The absence of committed and informed individuals, with an awareness of the impact of HIV/Aids on children, in a position of leadership within facilities and organisations.

4.1.1 Summary

According to researchers such as Johnson and Dorrington (2001) and Richter et al. (2004) an ideal situation would be to maximise the number and quality of contact opportunities with children and caregivers and to integrate the identification, support and monitoring of vulnerable children, wherever possible, into the daily activities of all relevant role players. The identification of vulnerable children can be facilitated by means of increasing the awareness of warning signs of vulnerability, and creating opportunities for children (and caregivers) to speak about and share their experiences and problems.

It is thus very important that further research should be done on the identified categories of vulnerable children and more specifically research on each category of children's psychological needs and the availability of services to these vulnerable children. The inherent strengths and weaknesses within these services that could be further developed or improved should also be assessed, as well as the most appropriate psychological ways of intervention and prevention to successfully identify and support these vulnerable children. Very important is the collaboration and networking between all stakeholders. The capacities of these stakeholders to facilitate more effectively the identification, referral, support and monitoring of vulnerable children should be strengthened. The monitoring of children who have received support is necessary to ensure that the support provided is sufficient, appropriate, and sustainable (Johnson & Dorrington, 2001; Richter et al., 2004; Wilson et al., 2002).

4.2 The psychological impact of HIV/Aids on the well-being of children

To gain some insight into the overall impact of HIV/Aids on children, including the psychological impact, it is necessary to look at statistics on the pandemic. According to statistics estimated in 2001, 800 000 children were infected with HIV and in 2002 alone an estimated 11.8 million adolescents and young adults between 15 and 24 were living with HIV/Aids (Foster & Williamson, 2000; Wilson et al., 2002).

Research suggests that approximately 9 percent of Sub-Saharan Africa children, under the age of 15 have lost at least one of their parents due to Aids. According to estimates, approximately 15 percent of children under the age of 15 will be orphaned by the year 2015

without significant changes in society's sexual behaviour patterns or adequate support initiatives (WHO, 2000-2004a, b). In South Africa one in six households with children are also caring for at least one orphan and the number of children living alone and in poverty is estimated to be on the increase. The number of children living alone and in poverty was estimated to be approximately 46 000 in 1996 and projected to be close to about 900 000 in 2011 (Johnson & Dorrington, 2001; Richter et al., 2004; UNAIDS, 2006; WHO, 2000-2004a, b). The expected impact of the abovementioned statistics is that the number of children at risk of being orphaned should double by 2010 if the response to the pandemic is not adequate. Without proper support initiatives that meet the needs, but especially the psychological needs of vulnerable children, a large number of them will grow up experiencing a huge variation of living conditions and psychological problems (UNAIDS, 2002, 2006; WHO, 2000-2004a).

Overall the literature reviewed indicates that the psychological impact HIV/Aids has on children in both South Africa and internationally has only been moderately researched over the past 4 years (2003-2006). The true extent and nature of the psychological impact on children from different age groups, contexts, and vulnerable categories is not clear. It therefore seems that additional research needs to be done on this topic. Numerous researchers have focused on the different forms of the impact the epidemic has on children living with HIV/Aids, including the psychological impact (Foster & Williamson, 2000; Fox et al., 2001; UNAIDS, 2006). In the opinion of the reviewer not enough researchers seem to have focused *solely* on the psychological impact that HIV/Aids has on children from different age groups, contexts and categories of vulnerable children.

For example research done the past 4 years (2003-2006), has only been highlighted in a few relevant and related articles such as the 2006 Report on the Global AIDS Pandemic (UNAIDS, 2006), the Human Sciences Research Council's situational analysis of orphans and vulnerable children (Davids & Skinner, 2005), and the Pakenham et al. (2006) article on the psychosocial impact of care giving on young people who have a parent with an illness or disability: *Comparisons between the impact of care giving on young child and adolescent caregivers and non-caregivers* (Davids & Skinner, 2005; Family Health International, 2005; Pakenham et al., 2006; Richter et al., 2004; UNAIDS, 2002, 2004, 2006).

Findings from reviewed literature do suggest that children's needs differ from the needs of adults. Often children's needs are neglected, but especially their psychological needs, and this impacts greatly on their overall well-being and development. Govender and Killian (2001)

addressed some effects on South African children exposed to chronic violent stressors. UNAIDS (2002, 2006) focused on several core needs and the psychological impact of HIV/Aids on children. Some of the fundamental developmental and psychological needs of children are the following: health and survival needs; safety and protection needs; stimulation and cognitive development needs; attachment needs; self-actualisation and identity needs; guidance and boundary needs, and appropriate inclusion and participation needs (UNAIDS, 2002, 2006; Wilson et al., 2002).

For the purpose of this review, attention will be briefly given to children's psychological needs (Wilson et al., 2002) that are often impinged upon by the pandemic: attachment needs, self-actualisation and identity needs, guidance and boundary needs, and appropriate inclusion and participation needs. Literature reviewed suggests that if children's psychological needs are not met the psychological impact on them will be vast (Desmond & Gow, 2002; Fox et al., 2001).

The HIV/Aids pandemic has forced immense numbers of children into uncertain circumstances. The pandemic psychologically impacts differently on children from different ages, genders and cultures, but ultimately children of all ages and young people are vulnerable to the psychological stressors that accompany HIV/Aids. Such stressors seem to lead to serious psychological and developmental problems (Berry & Guthrie, 2003; HSRC, 2003; Johnson & Dorrington, 2001; Richter et al., 2004; UNAIDS, 2004, 2006; WHO, 2000-2004a, b).

Research suggests the problem is that the psychological impact of HIV/Aids on children is the least visible and palpable. The psychological suffering and damage of children appear in various forms and can surface any time following a stressor, such as after the death of or during taking care of a parent or caregiver living with HIV/Aids. The death of a parent causes children to experience trauma and the loss of consistent nurture, the loss of guidance and increased concerns about the future. The constant experience of stress and trauma often makes it more difficult for the child to develop optimally and to be an integral part of society, with adequate coping and psychosocial skills (Fox et al., 2001; UNAIDS, 2006).

One of the most severe impacts on children, after illness and death itself, is the permanent loss of their parents' affection, support, and protection. The emotional shock of losing one parent may be inevitably followed by the death of the other parent or a significant family

member. Furthermore, the death of a parent often leads to the separation from siblings, as children are often sent to live in different households. In addition to the psychological trauma suffered by these children, poverty, social dislocation, the responsibility for the care of other family members, stigma, and discrimination can add to children's list of problems. All these problems increase children's vulnerability to HIV/Aids (Berry & Guthrie, 2003; Compas et al., 2001; Fox et al., 2001; HSRC, 2003; Richter et al., 2004; UNAIDS, 2004, 2006; WHO, 2000-2004a, b).

Research therefore suggests that children affected by and infected with HIV/Aids experience a profound and continuous sense of loss, grief, hopelessness, fear and anxiety, loss of constant nurture and guidance, and increased psychological distress. Psychological distress is often in the form of the loss of family and a sense of self-identity, depression, loss of educational opportunities, forced migration, increased street living, exposure to HIV infection, grieving, illness and death, anxiety and hopelessness, separation from siblings, and stigma, which often result in isolation and discrimination, and diminished love, attention and affection (Berry & Guthrie, 2003; HSRC, 2003; Johnson & Dorrington, 2001; Richter et al., 2004; UNAIDS, 2004, 2006; WHO, 2000-2004 a, b).

4.2.1 Summary

From the literature reviewed the observation can be made that the HIV/Aids pandemic appears to have a profound psychological impact on children. The pandemic seems to impact on many areas of children's lives and the impact on children and the larger society seems to be a complicated problem without an easy answer. The psychological impact of HIV/Aids on children's development and overall well-being is complex and the interrelationship of HIV/Aids with other problems of child development has become more apparent, but the long-term psychological impact of HIV/Aids is still not fully understood or has not been adequately researched (Family Health International, 2005; Richter et al., 2004; UNAIDS, 2002, 2004, 2006).

4.3 Children's coping with HIV/Aids

The devastating effects of HIV/Aids, such as the illness or death of a parent or caregiver, differs from child to child but despite the flexibility of children, the illness or loss of a parent or caregiver affects them. The problem is that children are often not able to cope with the devastating effects of living with HIV/Aids. The lack of the adequate coping skills and proper

environmental support then often leads to unfulfilled psychological needs, which in turn may lead to psychological problems and overall unwellness (Fox et al., 2001; UNAIDS, 2006).

Due to children's lack of adequate coping skills and support they often may not understand the impact of the pandemic on their lives and therefore are not able to express their grief effectively. Often children want to express their feelings, but there is no support available to them, such as someone to talk and listen to. Ever so often the disease process is not adequately explained to children and they are left to draw their own conclusions. This often creates various lasting problems for children such as in their interactions with family, peers and people in general. Therefore, in order for adults to help children through their grief, it is important that possible ways in which they might express their grief are identified (Fox, 2001; UNAIDS, 2006).

From research reviewed on children's coping with HIV/Aids in particular it appears that this area has been quite neglected. In the past 3 years research on coping has focused more on adolescents and adults and their problems related to adjusting to various different stressors, traumas, or life events. For example a study by Kemppainen et al. (2006) focused on the strategies for self-management of HIV-related anxiety by adults. Even though this type of research benefits our broader understanding of the psychological aspects of living with HIV/Aids, much needed research on children has been getting little or no attention, especially the specific healthy or poor coping skills of children living with HIV/Aids. Also, research studies in South Africa on coping in general have not focused on the coping of children. It has furthermore been found that research focusing on coping have looked at the coping and coping styles related to people's personalities; adult and adolescent coping related to mental health, and more specifically adolescent adjustment before and after HIV-related parental death or coping with the death of a parent due to illness or disease (Rotheram-Borus et al., 2005), and the survival strategies of HIV/Aids affected households in Soweto (Naidu & Harris, 2006). The findings are quite concerning because the specific characteristics of different stressors, trauma, violence, or life events require different types of solutions and coping processes from individuals, and in this case from children living with HIV/Aids. Therefore it is of the utmost importance that children's coping with HIV/Aids be researched to ultimately develop helpful ways of supporting children in need (Kemppainen et al., 2006; Naidu & Harris, 2006; Rotheram-Borus et al., 2005).

4.3.1 Summary

Research of the past 4 years on children's coping with HIV/Aids, was found to be sparse and neglectful. Even though some research was done, most of the research reviewed was done internationally and not as much in a South African context. When the severity and the impact of the pandemic as well as the projected increase in the number of children living with HIV/Aids is taken into account, the necessity for increased research focusing on the psychological aspects related to HIV/Aids, such as children's coping, becomes obvious.

Many children are struggling to cope on their own in child-headed households, because they frequently carry the burden of caring for family members living with HIV/Aids. South African children in general are especially vulnerable because they often do not have available to them the a healthy environment, which includes basic needs and the right to food, shelter, education, health, and psychological services – by means of which they would be able to protect themselves from HIV/Aids and other infectious diseases (UNAIDS, 2002, 2006).

It is of the utmost importance that the psychological needs of children, such as their attachment, self-actualisation/identity, guidance and boundaries needs, are met in order for them to develop adequate coping skills and to experience psychological and overall well-being (Compas et al., 2001; Fox et al., 2001; Kemppainen et al., 2006; Wilson et al., 2002).

4.4 Children's perceptions of HIV/Aids

The reviewed literature has pointed out the importance of taking into consideration the perceptions of children living with HIV/Aids (Fox et al., 2001; The Children's Institute, 2003-2004). The consideration of children's perceptions appears to be vital and strongly recommended in order to steer research and psychological support initiatives, such as programme development, in a successful and sustainable direction (Fox et al., 2001; Peltzer, 2003; The Children's Institute, 2003-2004). It has also been pointed out by research that children

> bring fresh perspectives to HIV/AIDS stories; that they reveal a range of different and unique stories, which contradict many of the widely held stereotypes about children. Children reflect and highlight varied experiences and views from different economic and cultural backgrounds. Children can tell you how they would like to be referenced and identified in news stories. Children have the right to participate in

> matters that concern them. As they too are affected by HIV/AIDS, they should be consulted for their views or experiences. (Bird et al., 2005, p. 22)

The importance of taking children's perceptions into consideration is further underscored by the list of children's rights in the United Nations Convention on the Rights of the Child and the South African Constitution (Prinsloo & Beckmann, 2000; UNAIDS, 2002, 2004). Related to this is a belief that has been upheld by the successful HUMULIZA programme that was implemented in Zimbabwe. According to the HUMULIZA programme children are more likely to respond well to support initiatives that have been influenced/codeveloped by themselves than when an adult introduces an intervention. One can deduce that in order to seriously and successfully respect, protect and fulfil children's rights, it is of the utmost importance that their perceptions and voices are heard, and their involvement in decision making is encouraged to ensure that their needs are met (Fox et al., 2001).

The review of international as well as local journal articles of the past 4 years (2003-2006) indicated that their focus was to a much greater extent on the perceptions and understanding regarding disorders and illnesses of orphans, adolescents, young adults and adults. Peltzer and Promtussananon (2003) also found research to be sparse, especially concerning African children's cognitions/perceptions and affective responses to HIV/Aids. Research also proved to be sparse regarding children's perceptions about their needs, especially their psychological needs (De Witt & Lessing, 2005; Pakenham et al., 2006; Peltzer & Promtussananon, 2003; Raman & Gelman, 2005; Rohleder & Gibson, 2006; Rotheram-Borus et al., 2005; Wooding et al., 2005).

Little focus seems to be placed on younger children's perceptions of the disease in its different stages; how their perceptions are presented regarding different categories of vulnerable children from different ages, demographic areas or contexts; what children need in order to cope better, or why they may feel they cannot cope. A lack of focus in this area might be due to the challenge it presents as far as gaining this type of information from younger children is concerned. Yet there are previous researchers on HIV/Aids who have pointed out that it is possible to gain this type of information from young children. The suggestion is however that the researcher should work according to a more qualitative approach and possess of the necessary skills such as sensitivity as well as great interviewing, research, and observation skills. More one-on-one or small-group interviewing and observations could also be more helpful (Power, 1998). Research of this nature is important because the perceptions,

attitudes and beliefs of children of different ages, genders, vulnerability categories and contexts will also develop differently and change over time. Children's perceptions should be considered for research and programme-development purposes in order for these initiatives to cater to children's specific needs and to be effective and achieve longer-term change (Peltzer, 2003; Peltzer & Promtussananon, 2003).

4.4.1 Findings from the review of South African literature

Some related South African articles were found but the focus of the literature was mostly on HIV positive women's perceptions on living with HIV/Aids; educator's views on the needs and support of HIV/Aids orphans in their psychosocial development, and the HIV/Aids/STD knowledge, attitudes, beliefs, and behaviours of a rural South African adult population (Pakenham et al., 2006; Rotheram-Borus et al., 2005; Wooding et al., 2005).

Further literature showed that the focus was on children's perceptions about preventing the transmission of HIV/Aids, or the perceived vulnerability to HIV/Aids among rural black South African children. Very few South African articles focused solely on children's perceptions about living with HIV/Aids and their needs - not only their material or medical needs but psychological needs as well.

South Africa, however, has shown some progress in this area as has been proved by initiatives such as the Dikwankwetla programme (The Children's Institute, 2003-2004), by the National Children's Forum (Berry & Guthrie, 2003), and Davids and Skinner's (2005) situational analysis of orphans and vulnerable children in four districts of South Africa. The pilot study by Peltzer and Promtussananon (2003) also contributed to some understanding of children's perceptions regarding their vulnerability. They found children's fears and perceptions of risk and vulnerability to have implications for current and subsequent behaviour. Yet it is merely a pilot study with a limited focus on children's perceptions regarding their vulnerability and it does not necessarily focus on other psychological aspects of living with HIV/Aids. More research will have to be done in this area.

The Dikwankwetla programme (The Children's Institute, 2003-2004) is a popular educational process that aspired to incorporate children's perceptions into all spheres of decision making, planning, intervention, and prevention that affect them. Through the Dikwankwetla process children were informed about the contents of the South African Bill of Rights and their opinions and recommendations were solicited.

According to children who participated in the Dikwankwetla programme, one of the greatest challenges children are currently facing is the grief that results from the loss of parents, siblings, relatives, and friends because of HIV/Aids. Children reported that the experience of loss and grief not only affected their physical well-being, but also their mental health and it therefore has to be addressed in all spheres of planning, intervention and prevention. According to the children who participated in the programme, it is essential to provide services such as free treatment, support, training, and counselling to all vulnerable children and families, but especially to children living with HIV/Aids. The children furthermore mentioned that they often suffered severe emotional trauma in dealing with loss and grief. They therefore required a number of more specific support strategies. The Children's Institute (2003-2004) stipulated some of these strategies. The whole community should be mobilised to offer support to vulnerable children by identifying and referring them to the relevant people. Communities could furthermore support such children by not discriminating against them. If the children have lost a caregiver, society must make sure that someone from their family or community will take care of them and not abuse them. There should be counsellors or other trained members in communities to identify these children and offer them support such as counselling. During the counselling process, death and all related aspects should also be explained and explored with the children.

The Children's Institute, from the University of Cape Town, also initiated the National Children's Forum on HIV/Aids (Berry & Guthrie, 2003). The forum invited 90 HIV /Aids affected South African children, aged 7 to 18 years. The goal of the forum was to give children the opportunity to discuss how HIV/Aids was impacting on their lives. The forum allowed children's opinions to be taken notice of by national decision makers. Completion of the forum confirmed the value of taking children's perceptions into consideration and to include children in decision making.

From feedback given by these children, similar key issues emerged as were reported by the children participating in the Dikwankwetla programme (Berry, & Guthrie, 2003; Davids & Skinner, 2005).

4.4.2 Findings from the review of literature from other African and international countries

In research done in Zimbabwe on children living with HIV/Aids a substantial number of child participants were identified as being vulnerable (Fox et al., 2001). Nearly a third of the participants reported that they did not feel able to cope. A further 22 percent of the participants mentioned that they did not have much hope for their future and 21 percent mentioned that they did not feel confident in themselves. The research also pointed out older children who were exposed to greater trauma and psychosocial distress and showed greater resilience than younger children. The older children reported more signs of psychosocial distress, such as feeling more alone, hopeless, worried or stressed (Fox et al., 2001).

Research done by Fox et al. (2001) and Gilborn et al. (2006) shared similarities in that child participants in both studies reported that they did not feel supported by their community or peers and that they felt abandoned by and unwelcome at family and friends. A number of orphans also reported that they did not feel that they had any adults to discuss their problems with.

International literature reviewed (Rotheram-Borus et al., 2005; Wooding et al., 2005) gave insight into adolescent's experiences with parental HIV/Aids. Similar to South African literature, very few international articles taken from the past 4 years have focused solely on children's perceptions on living with HIV/Aids and their needs.

4.5 Psychological support for children living with HIV/Aids

4.5.1 General background on psychological support and research

It has strongly been suggested that all forms of psychological support, such as programmes for and research on children living with HIV/Aids, should be underscored by the guidelines listed by national and international policies and plans such as those of the United Nations Convention on the Rights of the Child (UNAIDS 2002, 2004), Section 28 of the Bill of Rights in the South African Constitution (Prinsloo & Beckmann, 2000), the National Integrated Plan for Children (Desmond & Gow, 2002), and various others. Psychological support for children is very important. The United Nations has stated that children require support because they are especially vulnerable to abuse and in order for children to be physically healthy they also need to be psychologically secure.

The United Nations has recommended that support initiatives such as programmes for children and HIV/Aids should have a holistic and multidisciplinary approach, because children's psychological needs are complex, which necessitates various role players, including children, to work together (Fox et al., 2001; Wilson et al., 2002; UNAIDS, 2002).

According to the South African National Integrated Plan for Children and various other policies and plans such as the HIV/AIDS/STD Strategic Plan for South Africa and the South African Constitution (Desmond & Gow, 2002; Giese & Meintjies, 2003b; Meintjies & Giese, 2004; Prinsloo & Beckmann, 2000; UNAIDS, 2002) children living with HIV/Aids should be ensured access to comprehensive and complementary support services.

The National Integrated Plan for Children furthermore focuses on community-based care and support involving the development of care strategies, which include vulnerable children and people living with HIV/Aids. The programme also focuses on policy development and piloting approaches.

Lastly, the National Integrated Plan focuses on strengthening counselling and medical services. It also pays attention to life skills and HIV/Aids education in schools and lastly the plan focuses on community outreach/community mobilisation, which involves creating new HIV/Aids awareness campaigns and promoting already existing interventions (Desmond & Gow, 2002; Giese & Meintjies, 2003b; Meintjies & Giese, 2004).

4.5.2 Existing problems regarding research and psychological support initiatives, such as programmes in general

Many of the goals of the National Integrated Plan for Children, numerous other plans, support initiatives and research remain unattained and appear to be limited due to inadequate resources and poor inter- and intra-sectoral collaboration (Desmond & Gow, 2002). From the reviewed literature is would seem that limited attention has been given to the psychological needs of children in particular and it is the opinion of this reviewer that merely mentioning the importance of much needed services is not adequate as far as meeting the specific needs of vulnerable children is concerned.

The HIV/Aids pandemic has exposed problems within existing services, service infrastructures, research, and programmes. Like the pandemic itself, the problems inherent in research and support initiatives, such as programmes, can also be attributed to economic and social divide, poor inter-sectoral collaboration, and poverty (Giese, 2003). Inherent problems

in research and support initiatives seem to be the following: the role-players' lack of or poor focus, lack of consistency of approach, lack of specificity, and the lack of appropriate monitoring, evaluation and sustainability of research and programmes (Berry & Guthrie, 2003; Davids & Skinner, 2005; Desmond & Gow, 2002; Giese, 2003; Giese & Meintjies, 2003b; Meintjies & Giese, 2004).

A significant part of the burden of delivering services, such as research, programme development, and implementation regarding vulnerable children, is placed on community-based organisations, non-governmental organisations, and academic institutions (Giese, 2003). Often the basic responsibility of taking care of vulnerable children is left to communities and households. The problem in this regard is that the number of adult caregivers is decreasing and the number of vulnerable children is on the increase (Berry & Guthrie, 2003; Davids & Skinner, 2005; Giese, 2003).

Literature reviewed has shown that research and support initiatives concerning children living with HIV/Aids have in the past and recently as well, focused mostly on the material or educational needs of this special and vulnerable population. Very few support initiatives, such as programmes and research, have given adequate attention to specifically children's perceptions of and coping with HIV/Aids and also the psychological needs of children living with HIV/Aids. Many role players involved with issues related to children and HIV/Aids feel that the pandemic has increased the necessity to give the same attention to children's psychological problems as would be given to their other needs (Family Health International, 2005; Gilborn et al., 2006; UNAIDS, 2004).

4.5.3 General recommendations for psychological support and research

Many of the current and previous care and support services for South African children living with HIV/Aids are fragmented and uncoordinated. Numerous role-players share the same sentiment that children living with HIV/Aids do not just have medical needs but their needs are far reaching and therefore initiatives need to provide a variety of care services to children and their families living with HIV/Aids. The variety of care services must essentially attend to the medical, material, psychological, and emotional needs of children and their families (Abrahams & Shung King, 2001; Cotlands, 2003; WHO, 2000-2004a, b).

More current research in this area strongly recommends that HIV/Aids support initiatives, such as programmes and research, have a holistic and comprehensive approach. The 2001 UNAIDS principles support a holistic and comprehensive approach by stating the importance of empowering families and communities to respond to the needs, including the psychological needs of orphans and vulnerable children. UNAIDS also states the importance of involving young people and children in decision making and problem solving. Therefore it is very important to capture the perceptions and voices of children themselves (UNAIDS, 2002).

Literature suggests it is important to take into consideration the necessity of adult guidance and the empowerment of significant adults in children's lives to address the needs of children that emerge due to the HIV/Aids pandemic. In the past the family provided in a child's primary-care needs and the family was one of the most important influences in a child's life, but with the deterioration of families due to HIV/Aids, other sources are becoming more influential. Sources such as schools and teachers are other significant role-players. These role-players should be adequately trained to effectively address the psychological needs of children, and to recognise symptoms of vulnerability such as distress, depression, and abuse. Support initiatives should be implemented early in order to prepare children psychologically for the process the virus takes on, which includes overall deterioration and often the passing away of their parents or significant others. Further psychological support initiatives and research should be altered to mirror children's grieving processes, their attitudes towards, and perceptions of illness, loss, and death in their specific cultural context. Initiatives should focus on teaching children life skills and means of sustaining their livelihood, because these children become easy victims of exploitation, violence, abuse, and other trauma. The focus on support initiatives cannot just be at schools because increasing numbers of children are withdrawn from schools to care for ill parents, siblings or other family members, thus losing opportunities to acquire the necessary life skills needed for them to create sound and healthy households and living environments currently and in the future. This is why more initiatives must be implemented in communities and at home (Bradshaw et al., 2002; HSRC, 2003; Richter et al., 2004; UNAIDS, 2002, 2006; WHO, 2000-2004a, b).

It is important to ensure that the support initiatives and research are applicable to children living with HIV/Aids. Each initiative and research effort therefore needs to be tailored for each particular situation. The challenge is to adapt support initiatives and research to the South

African context in such a way that it will have a long-term effect on the lives of children in proportion to their needs.

Due to the lack of resources, both human and economic, support initiatives, such as programmes, should also be flexible and allow for non-specialists to be able to administer the intervention to children in need. The programme should be systematically monitored and evaluated throughout, and subject to rigorous experimental tests to establish the feasibility and impact of the programme. Many implemented programmes have not been evaluated and monitored closely and thus the efficacy and feasibility of such programmes cannot be established (Bradshaw et al., 2002; Compas et al., 2001; Richter et al., 2004; UNAIDS, 2004).

Various researchers have suggested that regarding research on psychological aspects, a more qualitative, phenomenological approach should be taken, especially when focusing specifically on children's perceptions, their coping strategies and psychological needs related to HIV/Aids (Gilborn et al., 2006; Phillip & Daniluk, 2004). It is suggested that a qualitative, phenomenological approach could provide a means of grasping the basic nature of how children living with HIV/Aids experience their identity. This type of approach will further allow children to articulate the role that HIV/Aids has played in terms of their past, their current life, and self-perception. It allows for a greater in-depth exploration of children's personal experiences and the meanings they assign to their experiences (Phillips & Daniluk, 2004).

The staggering HIV/Aids statistics urgently beckon us to address the psychological needs of vulnerable children from different genders, age groups, cultures, and contexts in equal proportion to other needs they might have related to the HIV/Aids pandemic. The pandemic impinges upon many of the fundamental rights of South African children and society's response or lack of response to the pandemic will be judged for generations to come. From literature reviewed one can deduce that a number of potential solutions to the problem do exist, for example the loveLife and Soul Buddyz initiatives. It is vital, though, that these support initiatives be put into place now and be cost effective, comprehensive, and sustainable. If we do not react quickly there will simply be an increase in the long-term costs to society, such as reduced literacy, poverty, crime, and violence.

It is, however, not realistic to merely expect the implementation of psychological support, such as programmes and research, to greatly reduce psychosocial distress. Therefore, broader

programmes, research, and policies to address economic and socio-cultural factors are needed (Fox et al., 2001; Gilborn et al., 2006; Mordaunt, 2003).

Support initiatives, research, and significant role players will only have a significant and sustainable impact on the lives of vulnerable children if they can successfully empower children, families, and communities living with HIV/AIDS to protect and care for vulnerable children (Desmond, & Gow, 2002; Gilborn et al., 2006; Johnson & Dorrington, 2001; Richter et al., 2004; UNAIDS, 2002).

5. SUMMARY

5.1 Findings and problems

This review is not an exhaustive study on all prior research done in relation to themes relating to psychological aspects of children living with HIV/Aids. The review only focused on some of the most current research done, internationally and in South Africa, during the past 4 years (2003-2006).

This review hoped i) to point out the importance of taking into consideration themes relating to the psychological aspects of children living with HIV/Aids such as their coping and perceptions when doing research and planning psychological support initiatives, such as programme development, ii) to notify the reader of the literature found related to these aspects, and iii) to indicate and clarify areas of research that need to be further explored, in order to inform research and adequate psychological support. The conclusion is that research and psychological support, such as programme implementation, will only have an ameliorating effect in relation to the suffering of children living with HIV/Aids if the psychological aspects of children living with HIV/Aids are thoroughly explored and thus the necessary support structures put in place (Fox et al., 2001; O' Brien, 2004).

Overall this review highlighted the significantly under-investigated, related and more specific research on psychological aspects of children living with HIV/Aids, both in South Africa and internationally.

5.1.1 Vulnerable children

Researchers such as Meintjies and Giese (2004) have shown that to date much of the attention paid to children's vulnerability due to the HIV/Aids pandemic has focused mainly on

providing support to orphans. It is strongly felt that an approach to HIV/Aids that focuses only on orphans as a special and vulnerable population, is not adequate regarding the South African context. Various researchers such as Skinner et al. (2004) feel that an approach that focuses only on support for orphans is not appropriate because orphanhood and children at risk to vulnerability, can be viewed as part of a process that begins well before a child experiences the death of a parent or caregiver with differently amalgamated vulnerabilities at different points along a continuum (Meintjies & Giese, 2004; Skinner, et al., 2004; UNAIDS, 2006).

Many role-players have proposed that the Government should adopt a bottom-up approach and this implies that the Government and all role players should take guidance from the community, and especially children themselves, when setting parameters for addressing the needs of vulnerable children living with HIV/Aids (Johnson & Dorrington, 2001; Richter et al., 2004; Skinner, et al., 2004; Wilson et al., 2002).

A working definition of vulnerable children, which includes children living with HIV/Aids, that is being used in South Africa by various researchers such as Johnson and Dorrington (2001), Richter et al. (2004), and Skinner et al. (2004), is as follows: vulnerable children can be defined as a special population of children or categories of children with specific and unique needs (Skinner et al., 2004) such as orphans (maternal, paternal or double orphans); neglected, destitute or abandoned children; children who have terminally ill parents or caregivers; children who are born of a teenage or single mother; children who are living with a parent or caregiver who has insufficient means or opportunities to generate an income or who are unemployed; children who are abused by a relative/parent or caregiver; children who are disabled, and children under the age of 15 who have lost their mother or caregiver (Johnson & Dorrington, 2001; Richter et al., 2004; Skinner et al., 2004; Wilson et al., 2002).

5.1.2 The psychological impact of HIV/Aids on the well-being of children

The HIV/Aids pandemic appears to have an extreme impact on children in many areas of their lives. The impact of HIV/Aids on children, their families, and communities cannot be seen as an uncomplicated problem with an effortless solution. The true extent and nature of the impact on children from different age groups, contexts, and vulnerable categories are not fully understood (Family Health International, 2005; Richter et al., 2004; UNAIDS, 2002, 2004, 2006).

Overall the review has found that specifically the psychological impact that HIV/Aids has on children in both South Africa and internationally seems to be only partially researched. Not enough researchers seem to have focused solely on the psychological impact that HIV/Aids has on children from different age groups, contexts, and categories of vulnerable children. Often researchers focused more on adolescents, young adults and adults, and not as much on young children. It was also found that many researchers did not ask children themselves how they perceived the pandemic and how it impacted on them psychologically. (Davids & Skinner, 2005; Family Health International, 2005; Pakenham et al., 2006; Richter et al., 2004; UNAIDS, 2002, 2004, 2006).

5.1.3 Children's coping

Research done the past 4 years on children's coping with HIV/Aids, was found to be sparse and neglected. Even though some research was done between 2003 and 2006, most research reviewed was done internationally and not enough in South Africa.

Many children are struggling to cope and South African children in general are especially vulnerable because they often do not have available to them the basic healthy environment, which includes basic needs and the right to food, shelter, education, health, and psychological services – by means of which they can protect themselves from HIV/Aids and other infectious diseases (UNAIDS, 2002, 2006).

The lack of adequate coping skills that according to Kemppainen et al. (2006) implies self-care and management strategies such as self-comforting behaviours, help-seeking behaviours, self-talk, avoidance or unhealthy coping behaviours, and proper environmental support will lead to unfulfilled psychological needs, which in turn will lead to psychological problems and overall unwellness (Kemppainen et al., 2006).

5.1.4 Children's perceptions

Reviewed literature of the past 4 years (2003-2006) suggests that neither international nor local researchers have focused on the perceptions and understanding with regard to disorders and illnesses of orphans, adolescents, young adults and adults. Peltzer and Promtussananon (2003) also found research to be sparse especially regarding African children's cognitions/perceptions and affective responses to HIV/Aids, together with their perceptions about their needs, especially their psychological needs (De Witt & Lessing, 2005;

Pakenham et al., 2006; Peltzer & Promtussananon, 2003; Raman & Gelman, 2005; Rohleder & Gibson, 2006; Rotheram-Borus et al., 2005; Wooding et al., 2005).

Little focus seems to have been placed on younger children's perceptions of HIV/Aids at different stages of the disease, on how these perceptions present regarding different categories of vulnerable children from different ages and demographic areas or contexts, or on what it is that children need to cope better, and why they perhaps feel they cannot cope. A lack of focus in this area might be due to the fact that it is a challenge to gain this type of information from younger children. Previous researchers on HIV/Aids, however, have pointed out that it is possible to gain this type of information from young children. It has been suggested that a more qualitative approach should be used; that the researcher should possess of the necessary skills, such as sensitivity, as well as enhanced interviewing, research and observation skills, and that one-on-one or small-group interviewing and observations should rather be done (Power, 1998). Research of this nature is important because the perceptions, attitudes, and beliefs of children of different ages, genders, vulnerability categories, and contexts will also develop differently and change over time. Children's perceptions should be considered for research and programme development purposes in order for these initiatives to cater to children's specific needs and in order to be effective and bring longer-term change (Peltzer, 2003; Peltzer & Promtussananon, 2003).

5.1.5 Psychological support for children living with HIV/Aids

Many of the goals of the National Integrated Plan for Children and numerous other plans and psychological support initiatives developed by Government and other role players, remain unattained and appear to be limited due to inadequate resources and poor inter- and intra-sectoral collaboration (Desmond & Gow, 2002). Limited attention has been given to the psychological needs of children in particular and merely mentioning the importance of mental health services, such as counselling services, is not enough to meet the specific needs of vulnerable children.

The HIV/Aids pandemic has exposed problems within existing services, service infrastructures, research, and programmes that have been in operation for an extensive period. Similarly, problems inherent to research and support initiatives, such as programmes, are to some extent the result of economic and social inequalities, poor inter-sectoral collaboration, and poverty. Research problems also seem to be due to researchers

themselves, lack of consistency of approach, lack of specificity, as well as the lack of appropriate monitoring, evaluation and sustainability of research and support initiatives (Berry & Guthrie, 2003; Davids & Skinner, 2005; Desmond & Gow, 2002; Giese, 2003; Giese & Meintjies, 2003b; Meintjies & Giese, 2004).

Most interventions and research have been done piecemeal and have not matched the scale of the problem the pandemic has created. Many role players involved with aspects related to children and HIV/Aids feel that the HIV/Aids pandemic has augmented the need to address psychological problems of children (Family Health International, 2005; Gilborn et al., 2006; UNAIDS, 2004).

5.2 General recommendations for research and psychological support

Various researchers have suggested that a more qualitative, phenomenological approach be taken with research on themes relating to psychological aspects especially when focusing specifically on children's perceptions, coping strategies and psychological needs related to HIV/Aids (Gilborn et al., 2006; Phillip & Daniluk, 2004). It is suggested that a qualitative, phenomenological approach could provide a means of grasping the basic nature of how children living with HIV/Aids experience their identity. This type of approach will further allow children to articulate the role that HIV/Aids has played in terms of their past, their current life, and self-perception. It allows for a greater in-depth exploration of children's personal experiences and the meanings they assign to their experiences (Phillips & Daniluk, 2004).

The major concern related to these findings is that the severity and the impact of the pandemic are increasing and the current and projected statistics for children affected by and infected with HIV/Aids are on the increase. In South Africa alone the pandemic is cause for major concern and therefore it could expected that more recent research would be devoted to aspects impacting on children and more specifically the psychological aspects of children living with HIV/Aids. Even though numerous role players, including the South African Government, have stressed the importance of this type of research and programme development, not much seems to have been done.

It is thus very important that further research be done regarding the various categories of vulnerable children that exist and more specifically research on each category of children's psychological needs, the psychological impact of living with HIV/Aids, and also the availability

of services to these vulnerable children. The way children cope with and perceive HIV/Aids should also be explored further. Research should be done on the inherent strengths and weaknesses within the support services that could be further developed or changed. The most appropriate psychological forms of intervention and prevention are to successfully identify and support these vulnerable children. Very important is the collaboration and networking between all stakeholders. The capacities of these stakeholders should be strengthened to more effectively facilitate the identification, referral, support and monitoring of vulnerable children. The monitoring of children who have received support is also necessary to ensure that the support provided is sufficient, appropriate, and sustainable (Govender & Killian, 2001; Johnson & Dorrington, 2001; Kemppainen et al., 2006; Peltzer, 2003; Peltzer & Promtussananon, 2003; Richter et al., 2004; Wilson et al., 2002).

6. CONCLUSION

Themes relating to psychological aspects of children living with HIV/Aids include all issues related to children's mental/psychological well-being or development, such as their psychological needs at different ages, how they develop, how they cope with certain stressors or trauma, and their perceptions of different aspects. These psychological aspects all impact greatly on their psychological well-being (Bradshaw et al., 2002; Family Health International, 2005; Fox et al., 2001; HEARD, 2002; HSRC, 2003; UNAIDS, 2004; WHO, 2000-2004a, b & Wilson et al., 2002).

Being part of a nation in crisis it is the responsibility of South African adults to address the HIV/Aids pandemic in such a way that the response would lead to a more hopeful and healthy present and future for South African children.

Research and support initiatives that focus on the psychological impact of HIV/Aids, on children's coping with and their perceptions of HIV/Aids, and on their psychological needs related to HIV/Aids, have been flagrantly disregarded. The psychological impact of HIV/Aids seems to be the least evident and extremely difficult for adults to address or understand and yet a child's physical well-being and psychological health cannot be separate from one another. It seems as though a child cannot be physically healthy without being psychologically stable (Bradshaw et al., 2002; Family Health International, 2005; Fox et al., 2001; UNAIDS, 2002, 2004; HEARD, 2002; HSRC, 2003; WHO, 2000-2004a, b; Wilson et al., 2002).

More current research in this area strongly recommends that HIV/Aids support initiatives and research need to be holistic, comprehensive, and sustainable. It is very important to empower families and communities to meet the psychological needs of vulnerable children. It is very important that children participate in prevention, intervention, care, support, decision making, and research (Fox et al., 2001; Gilborn et al., 2006).

The challenge is to rethink research and adapt support initiatives to the South African context in such a way that the initiatives and research will make a significant difference in the lives of children living with HIV/Aids.

It is of the utmost importance that children's rights are respected, protected, and fulfilled. Children's voices must be heard, their involvement in decision making must be allowed, and their needs must be met, especially their psychological needs (Bradshaw et al., 2002; HSRC, 2003; Richter et al., 2004; UNAIDS, 2002, 2006; WHO, 2000-2004a, b).

A child's world at times might seem quite small and insignificant to adults, but to children the daily circumstances they find themselves in means everything to them and therefore adults need to respond to their outcry to make them overall healthy and productive adults of tomorrow.

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